



The significance of stress in parents of a child with Autism Spectrum Disorders

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The literature review focuses on the importance of stress in parents of a child with autism spectrum disorders, which significantly affects family life. The main cause of the burden are accompanying difficulties that are the part of disorder. This applies to specific reactions such as fits of anger, self-harm, psychomotor agitation, eating disorders, sleep disorders and other troubles which require almost 24-hour care. This review assesses several research studies that deal with the issue and which can be examples of good practice.

KEY WORDS: stress, family, Autism Spectrum Disorders, child

Introduction

Pervasive development disorders (including ASD, Autism Spectrum Disorders) belong to the most significant mental development disorders in children. They fuse in themselves many specific symptoms (problems with social interactions, communication, stereotypical and repetitive behaviour) as well as non-specific ones that for the most part influence the general functioning of the family. The

term 'pervasive' expresses the fact that they permeate all aspects of life, and that hence the development of a child is deeply disturbed in many respects. The concept of autism spectrum disorders is more precise, as the original manifestation is rather (spectral) diversity than the intertwining of many areas (ever-present)¹.

The new version of the DSM, DSM-5, made the identification of disability more effective through the removal of speech development delays from the area of symptoms, leaving two areas - social communication disturbances and stereotypical, rigid behaviour². This is confirmed by the study of Tsai³, according to which 9-54% of cases diagnosed according to DSM-5 does not fulfil the diagnostic criteria for autism spectrum disorders. The diagnosis of disorders could in particular be made more precise by the level of gravity and further details such as the presence or lack of mental disability, speech impairments or a genetic illness.

Persons with significant signs of autism require almost round-the-clock care, as significant deficits in the individual aspects of family life, in particular the child itself, are very limiting (APA)⁴. Almost 70% of persons with autism develop another mental disease that in practice goes undiagnosed and which weakens their psycho-social activity⁵.

According to Janzen⁶, parents are frequently able to interpret the behaviour of their children. They are able to guess the signals indicating an elevated level of stress and the possibility of intensification of unwanted behaviour. In general, we say that when stress

¹ K. Thorová, *Poruchy autistického spektra*, Praha, Portál, 2006

² M. Hrdlička, V. Komárek eds., *Dětský autismus*, Praha, Portál, 2004.

³ Tsai L.Y., Impact of DSM-5 on epidemiology of Autistic spectrum disorder. In *Research of Autism spectrum disorders*, 2014.

⁴ American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders - 5th edition. Arlington: VA, American Psychiatric Publishing, 2013.

⁵ NICE. Clinical guideline 128. Autism diagnosis in children and young people. Recognition, referral and diagnosis of children and young people on the autism spectrum, 2011.

⁶ J.E. Janzen, *Autism, facts and strategies for parents*, Texas, Therapy skill builders, 1999.

increases, intensity increases as well, causing a chain reaction in behaviour. This could shine through in the following:

- 1) physical symptoms (frustration, disquiet, tiredness, changes in breathing),
- 2) repetitive verbal or motor behaviour (repetition of questions related to time or events, spinning fingers, rocking),
- 3) disorganised behaviour,
- 4) symptoms of apathy, the loss of motivation, covertness, closing eyes, banging the table with the head,
- 5) signs of protest (fleeing, destroying objects),
- 6) emotional outbreaks (laughter somebody is injured, shouts),
- 7) self-harm (hitting oneself on the head, hitting oneself with a fist),
- 8) aggression (pinching, scratching, punching, kicking).

The Autism Society with its seat in the state of Maryland (United States) indicates that stress in families of children with autism spectrum disorders is a daily routine (Autism Society). This applies to normal behaviour such as shopping, bathing, preparing food, spending free time, the course of which remain on a completely different level than in the case of families of children without these disturbances⁷. According to the University of Wisconsin, the level of stress in parents of children with autism is comparable to stress of war veterans⁸.

⁷J. Bimbrahw, J. Boger, A. Mihailidis, *Investigating the efficacy of a computerized prompting device to assist children with autism spectrum disorder with activities of daily living*. In Assistive technology, 2012; Hong E., Ganz J., Ninci J., Neely L., Gilliland W., Boles M., *An evaluation of the quality of research on evidence-based practices for daily living skills for individuals with ASD*. In Journal of autism and developmental disorders, 2015. Labosh K., *Stress: Take a load off*. In Autism advocate, 2005; Weaver L.L., *Effectiveness of work, activities of daily living, education and sleep interventions for people with autism spectrum disorder: A systematic review*. In American Journal of Occupational Therapy, 2015.

⁸M.M. Seltzer, J.S. Greenberg, J. Hong, L.E. Smith, D.M. Almeida, C. Coe, R.S. Stawski, *Maternal cortisol levels and behavior problems in adolescents and adults with ASD*, In Journal of Autism and Developmental Disorders, 2010.

Benson⁹ indicates that parental depression is related to the gravity of autism spectrum disorders in children. He speaks of proliferation of stress, which was discovered in 68 parents of children with autism spectrum disorders. Proliferation of stress is the tendency of stressors to give rise to further stressors in other areas of life. According to the regression analysis, depression in parents may be related to increased symptoms in their children, as well as the proliferation of stress, which influenced the emergence of stronger symptoms in children and of depression in parents. Benson¹⁰ also notes that informal social support reduces the level of stress in parents, but that its proliferation is directly related to the gravity of the condition of the child, significantly influencing the development of the mental disorder in the parent.

As indicated above, care for a child with autism spectrum disorders brings with itself great burdens that impact negatively on the physical and mental health of the family as well as other people caring for the child¹¹. In this context, much research focuses rather on the quality of life of the parents¹² than on the stress itself.

The burdens that the parents of a child with autism spectrum disorders must cope with are frequently not aligned with the stud-

⁹ P.R. Benson, *The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation*. In *Journal of autism and developmental disorders*, 2006.

¹⁰ *Ibidem*.

¹¹ J.B. Gorlin, C. McAlpine, A. Garwick, E. Wieling, *Severe childhood autism: the family lived experience*. In *Journal of pediatric nursing*, 2016.

¹² M. Hrabovecká, *Kvalita života rodičov detí s autizmom*. In *E-Psychologie*, 2015; R.L. McStay, D. Trembath, CH. Dissanayake, *Maternal stress and family quality of life in response to raising a child with autism: from preschool to adolescence*. In *Research in developmental disabilities*, 2014; D. Mugno, L. Ruta, V.G. D'arrigo, L. Mazzone, *Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder*. In *Health and Quality of Life Outcomes*, 2007; L.C. Lee, R.A. Harrington, B.B. Louie, C.J. Newschaffer, *Children with autism: Quality of life and parental concerns*. In *Journal of autism and developmental disorders*, 2008.

ies that we find in the context of handling them, or with specific possibilities of coping with them¹³.

Wang¹⁴ concentrated his research on children from 368 families that show autism spectrum disorders from the People's Republic of China and compared them to families of children with other developmental disorders. Both groups experienced a high level of burdens, but the most commonly applied strategy in raising children with autism spectrum disorders was exactly planning. In the sample of Chinese families, however, these were dominated by fears for the future of their children due to factors typical for the People's Republic of China – the lack of qualified specialists working with children with autism spectrum disorders, no possibility of educating these children, the financial burden for rehabilitation, education and in the end the fear of the parents as to what will happen to their children after they die.

Bilgin and Kucuk¹⁵ have conducted a survey based on a semi-structured interview with 43 mothers from Turkey, focusing on their experiences, their lives, their support options, the strategies of managing burdens and educational capabilities. In the Turkish family system, solidarity and mutual support are common values, but the difficulty of some stressful situations in the life of a child with

¹³ M.J. Baker-Ericzen, L. Brookman-Frazee, A. Stahmer, Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. In *Research and Practice for Persons with Severe Disabilities*, 2005; B.A. Boyd, Examining the relationship between stress and lack of social support in mothers of children with autism. In *Focus on Autism and Other Developmental Disabilities*, 2002; N.O. Davis, A.S. Carter, Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. In *Journal on Autism and Developmental Disorders*, 2008; C.D. Hoffman, D.P. Sweeney, D. Hodge, M.C. Lopez-Wagner, L. Looney, Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. In *Focus on Autism and Other Developmental Disabilities*, 2009.

¹⁴ P. Wang, C.A. Michaels, M.S. Day, Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. In *Journal of Autism and Developmental Disorders*, 2011.

¹⁵ H. Bilgin, L. Kucuk, Raising an autistic child: Perspectives from Turkish mothers. In *Journal of child and psychiatric nursing*, 2010.

autism spectrum disorders may also influence the cultural attitudes of religious origin. Perceiving autism from the point of view of multiculturalism as a significant factor in the life of a family is discussed within a broader spectrum by Dyches¹⁶.

Janzen¹⁷ indicates that one of the most fundamental rules of care for a child with autism spectrum disorders is understanding its behaviour. It is exactly the difficult-to-handle behaviour of the child that causes additional reactions that are part of the disorder and cause the most stress in the parents. According to Janzen¹⁸, the most important strategies of coping with such behaviour are: preventive care and preventing the worsening of behaviour. The achievement of these objectives is ensured by parents, teachers, assistants, mentors, siblings or persons acting as facilitators. In order to better understand the level of burden in course of care for a child with autism spectrum disorders, Janzen¹⁹ had determined four levels of stress, in which he described primarily the objective and task of the facilitator himself:

1. *When the stress increases and unwanted behaviour intensifies.*

Objective of the facilitator: reduce the stress and avoid a crisis.

Task of the facilitator: identify the behaviour indicating such a stress reaction (disquiet, rocking, redness of the face, change of breathing rhythm or behaviour); be able to notice such a reaction/information; react to the problem and suggest a solution; provide assistance in solving the problem, avoid the crisis.

*Good practice*²⁰: important is getting to know the motivational factors of a child (toy, food, activity, person) in order to prevent the tension from escalating, and to have them handy.

¹⁶ T.T. Dyches, L. Wolder, R.R. Sudweeks, F.E. Obiakor, B. Algozzine, Multicultural issues in autism. In *Journal of autism and developmental disorders*, 2004.

¹⁷ J.E. Janzen, *Autism, facts and strategies for parents*. Texas: Therapy skill builders, 1999.

¹⁸ Ibidem.

¹⁹ Ibidem.

²⁰ Under the heading of Good practice, the author of the article presents her experiences from practice that have proven themselves during work with a child with

2. *When the child is hypersensitive or out of control; crisis level.*

Objective of the facilitator: protect people

Task of the facilitator: if there is time for this, take the child to a location where it will have the possibility of calming down, if there is no time for this, remove the persons to another place to protect them from potential danger; quickly solve the problem and let go of the load; remain calm and redirect the interest of the child elsewhere; give way and leave more space for the child; stop talking; do not forget that the child is in a state of panic and that in that moment it is not able to think; protect people; try to avoid damage and injuries; a cautious approach or having permanent protection handy is necessary (in this case, it is not an intervention programme or time for learning. In a state of crisis, the child neither able to think nor learn.).

Good practice: the effort leading to a reduction of the potential threat to the child (if it has a tendency to self-destruct) from other children, removing it to a different room, directly burdening the child with your own body and strength, or removing everything in the direct neighbourhood as far away from it as possible; reflect its behaviour (as an intention of communication, making contact).

3. *Calming and minimising the escalation of behaviour.*

Objective of the facilitator: aid the child in returning to its prior activities.

Task of the facilitator: remain close, calm and quiet, one should not make any demands of the child; if the child begins to calm down, support them with the words: "This is good, remain calm, everything will be all right..."; if the child is completely calm, prepare for it some kind of further task: „When the bell rings, it's time for..."; it's good to support the next task with some visual sheet, an object, a table with daily activities.

Good practice: after the passage of increased tension, fluidly move on into another activity and continue the daily routine, the

autism spectrum disorders. However, always consider the current condition of the child and the intensity of disturbances.

transition to a different activity [should be] supported by an information sheet, motivate the child to change its activity, let the child know your emotions immediately after its behavioural attach (consider – depending on the progress of the condition).

4. *Calm and stable behaviour, a condition of balance.*

Objective of the facilitator: maintain the level of tension of the child at such a level that it is alert, but not at a level that would cause it to lose control; teach it new skills when it is in a state of calm and when it is able to learn.

Task of the facilitator: foresee and prevent possible problems in such a way so that the child could be prepared for new and unknown situations; continuously observe its level of tension; if an unforeseen problem emerges, attempt to solve it as quickly as possible, reduce the tension and in this manner prevent a crisis; teach the child new skills spanning the prevention of recurring problems, e. g. plea for help, teach it relaxation techniques so that it is able to express its need for a break, continuously evaluate and improve the organisation of space, materials, the daily routine, individual activities, the daily life style, and connect necessary expectations with the needs of the child, be able to organise an environment suitable for learning.

Good practice: getting to know the components of a child's motivation as a mode for progress; the significance of the relation with the child; know its phobias, joys and functioning in ordinary life (communication with parents).

New research²¹ shows that 99% of adults with autism and their caretakers indicated that stress is important for them, whereby 93% of them add that it is very difficult or even impossible to find effective help in controlling stress. It was furthermore concluded that:

- 98% of parents (caretakers) state that it is difficult or impossible to find efficient support for their children,
- 81% adults with autism state that stress has significant or even very significant influence on the self-esteem confidence,

²¹ Research Autism. *Beating stress in autism*, [online]. London 2017.

- 74% adults with autism state that stress has significant or even very significant influence on sleep,
- 95% parents (caretakers) state that stress has significant or even very significant influence on the upbringing or work of their children,
- 88% parents (caretakers) state that stress has significant or even very significant influence on the behaviour of their children,
- 86% adults with autism state that stress has significant or even very significant influence on their mental health,
- 84% parents (caretakers) state that stress has significant or even very significant influence on the relations of their children,
- 63% adults with autism spectrum disorders state that their current strategies of managing stress are ineffective.

Additionally, tension and stress are frequently considered to be synonyms. Stress defines borderline forms of tension states, in which the threat to life or individual integrity requires an exceptional activation of the system of self-control. Lazarus and Folkman²² describe stress as a *“specific relationship between a person and the environment, which in view of persons makes excess demands exceeding their capabilities and threatening their health”*. Along with the inability to cope with this relationship or adaptation, there emerges the risk of weakening of physical and mental health, which significantly intervenes in changes to the structure and dynamics of work that causes stress situations²³. According to Strmeň, Raiskup²⁴, tension is a factor influencing the body that stresses demands that interfere with the balance in the body, stimulating work aimed at its restoration. The mentioned authors stress higher requirements related to

²² R.S. Lazarus, S. Folkman, *Stress, appraisal and coping*. New York, Springer, 1984, p. 19.

²³ M. Bratská, *Zisky a straty v záťažových situáciách alebo príprava na život*. Bratislava: Práca, 2006, p. 305.

²⁴ L. Strmeň, J.Ch. Raiskup, *Výkladový slovník odborných výrazov používaných v psychológii*. Bratislava, IRIS, 1998.

sensory, mental, independent processes and capacities of man. Stress and tension emerge when the measure of burdening factors is higher than the measure of a person to handle the situation²⁵.

The evaluation of burdens in the care for a child with autism spectrum disorders never reflects the experiences of parents, who as a result of these daily disturbances find themselves in difficult situations. On the basis of numerous studies mentioned above, it may be concluded that the diagnosis significantly influences the quality of life of the family. The case is not just the internal family environment (siblings, partner relations and their intimacy, spending free time, etc.), but also support and understanding from the external environment (closest family, society), which in the 21st century exhibits stereotypical reactions and marks these children as misbehaving and badly educated.

The burden of the family encompasses a certain stigma, difficulties in managing the child's behaviour, challenges related to care, social isolation and mentioned altered dynamics within the family. An enormous volume of factors, with which the family of a child with autism spectrum disorders copes leads to everyday battles, which intersect at a single point – the need of support.

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²⁵ R. Šerfelová, *Závaž opatrovateľa počas starostlivosti o zomierajúceho*. Martin, JLF UK, 2012.

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